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ABSTRACT

This report describes the current status and needs of chronically ill children and their families in Oregon. An introductory chapter outlines the history of educational services for children with severe health needs, defines the term "chronically ill," reports on prevalence, and outlines trends. a survey of 49 parents of chronically ill children analyzes demographic information, access to and need for various services, changes that would improve service delivery, and types of financial assistance being received. The primary roles of state agencies which could provide support and services are described. The report recommends that the state: (1) continue the Steering Committee on Children with Chronic Illness and Their Families; (2) designate and fund a single case management agency; (3) include parents as important planners, reviewers, and evaluators of goals, objectives, and action plans; (4) coordinate and extend eligibility criteria to assure that all children with severe chronic illnesses qualify for medical support and other services; (5) assure a support system that addresses the financial needs of all parents; (6) provide support to assure that children with chronic illness progress through the public school system; and (7) provide training for service providers. An appendix contains a copy of the parent survey form. (JDD)

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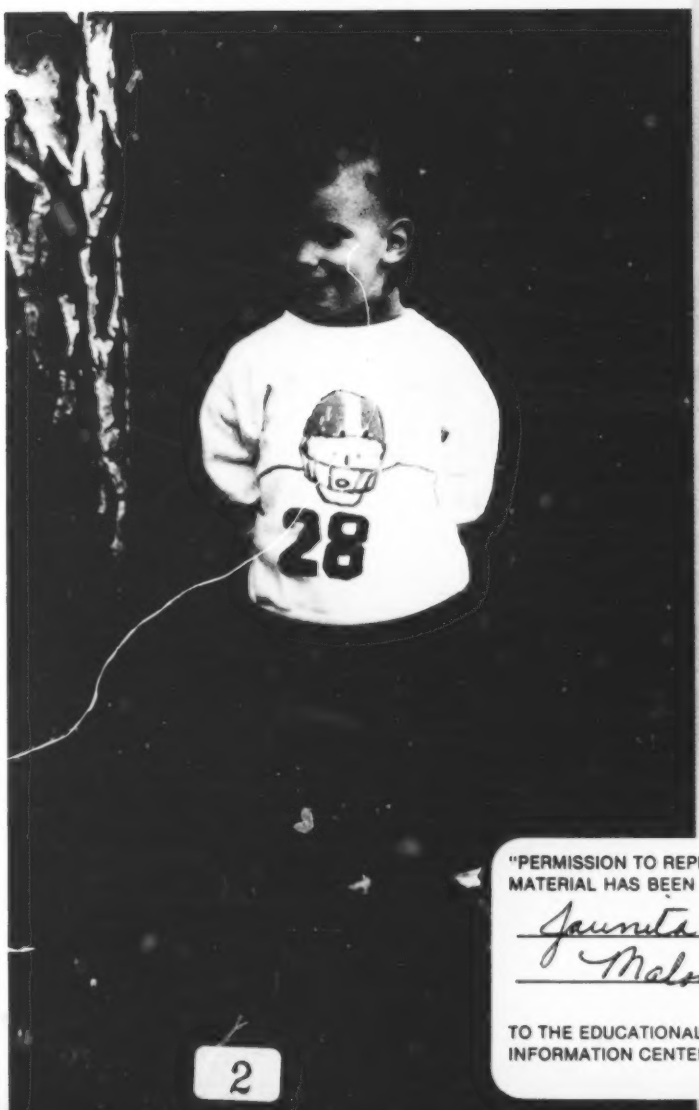
On the Agenda:

Oregon's Chronically Ill Children and Their Families

1989



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On The Agenda:
Oregon's Chronically Ill Children and Their Families

1989

Prepared for
The Oregon Department of Education
Salem, Oregon

Steering Committee on Children with Chronic Illness
and Their Families

Prepared By
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Preface

This report is in response to the concerns of parents, educators, health professionals, and advocates who are looking for legislative and agency assurance that children with chronic illness will receive necessary medical care and educational services and that their families will receive the basic support they need.

Taking the initiative from a Legislative Budget Note* a Steering Committee on Children with Chronic Illness was formed in January, 1988 and charged with the production of a plan for providing services. The Steering Committee included representatives from primary agencies which provide support to families with chronically ill children. It also has a representative from a state parent and advocacy group. The committee met regularly to begin the development of a state plan for providing services to children who are chronically ill and their families. Currently this development work includes: 1) a draft of a definition of chronic illness; 2) identification of the critical needs of children who are chronically ill, their families and service providers; and 3) the development of a forum through which agencies can communicate.

This report, *On the Agenda: Oregon's Chronically Ill Children and Their Families*, has been commissioned by the Oregon Department of Education to describe the current status and needs of chronically ill children and their families and to address the major concerns of consumers, advocacy groups, and supporting agencies.

*Budget Note to the Oregon Department of Education from 1987 Legislative Assembly

"The subcommittee directed the Department of Education to identify a half-time specialist within its existing budget to assist the Department in developing and delivering technical assistance to school districts about appropriate educational services for children with severe and chronic medical needs. The subcommittee further expects that the Department will convene a steering committee of representatives of the following agencies and groups: Children's Services Division, Mental Health Division, Adult and Family Services Division, Child Development and Rehabilitation Center, Vocational Rehabilitation Division, parents, and service providers. The responsibility of the steering committee is to produce a plan that includes a statement of need, demographic analysis, population, and proposed legislation. Both the Department of Education and the Department of Human Resources shall report their accomplishments to the 1989 Legislative Assembly.

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This state has got to accept the responsibility of making children our priority ... Children are our most valuable resource and they need to be treated accordingly. They are more valuable than any monetary unit ... Not one human being can be overlooked."

Oregon Parent
Association for Severely Other Health Impaired Children

Executive Summary

Many parents, professionals, and advocates feel that children with chronic illnesses have been a relatively neglected group. Children with developmental disabilities, with orthopedic impairments, children who are hearing or vision impaired, or those who have autism have been receiving attention for many years. There are model programs for these children in public school systems, transition programs for vocational and residential facilities, and grant monies for systems change. Children with chronic illnesses, however, are not mentioned in legislation and have not received the same attention as other populations of children with impairments.

There is now a growing body of excellent research which describes the needs of chronically ill children and their families. There are also several model programs for providing services. This section includes a discussion of key issues that surround the delivery of services to chronically ill children and their families. These key issues include:

1. The continued development of a State Plan
2. Formal case management
3. Normal patterns of family living
4. Eligibility for services
5. Financial support
6. Public school education
7. Training

Formation of the Steering Committee on Children with Chronic Illness and Their Families

In January a Steering Committee was organized to develop a plan of action for improving services to children with chronic illnesses and their families. The Steering Committee is composed of representatives from a parent group and key human service agencies who meet regularly to identify service needs and to discuss approaches to meet those needs.

Definition of Severe Chronic

The focus of the Steering Committee has been children with severe chronic illnesses. The Committee uses the term severe chronic illness to include those health conditions in which:

"... the absence of immediate health-related special skilled care threatens the life or health of the child and the child requires a medical protocol to ensure his or her safety; and there is no foreseeable end to this condition."

Numbers of Children with Chronic Illness in Oregon

There is no current and systematic count of the number of infants and children, birth through 21, who are chronically ill in Oregon. Estimates from the Oregon Department of Education and Providence Child Center place the incidence of chronically ill children at about 1,000. This figure fits the national prevalence data which indicates that about 1% to 2% of the children's population has severe chronic illnesses.

On The Agenda: Recommendations of This Report

Throughout the United States there is a growing recognition of the need to develop services for chronically ill children and their families. In many states, including Oregon, task forces are being formed to design effective service delivery models; organizations are continuing their research into the causes,

prevention, and cures for chronic illnesses; and advocacy groups are forming to support families, to help pass legislation, and reform state policies.

These groups consistently voice a similar set of values and make the same types of recommendations about the ways support should be provided. They consistently advocate for the necessity of trained staff who can provide accurate information and assistance in identifying and coordinating appropriate services, for financial support that will help alleviate the distress of high medical and associated costs, for service systems that promote adequate care in a child's home, for training that will prepare teachers and staff in state agencies to meet the needs of children with chronic illness, and for a service and funding structure that relies on parents and other advocates to direct service efforts.

The authors of this report and the members of the Steering Committee recognize that the development of a State Plan for delivering services to chronically ill children and their families cannot be accomplished in a year. The process of thoroughly implementing a plan may take five to ten years. The recommendations of this report are limited to those activities that can be accomplished during the next biennium.

1. Continue the mandate for a Steering Committee on Children with Chronic Illness and Their Families.

In addition to providing a forum for coordinating resources, a primary task of the Steering Committee should be the continued development of a State Plan that specifies the adoption of a mission statement, goals, objectives, timelines, and responsibilities.

2. Designate and fund a single agency through which parents can access information about services and can access case management of services for children with chronic illnesses.

To begin this process, move responsibility for facilitating the continued development of a State Plan for chronically ill children and their families from the Oregon Department of Education to the Department of Human Resources. These responsibilities will require funding for at least a full time staff person, either FTE or contracted, and a secretarial position to coordinate the efforts of the Steering Committee and to provide information to consumers and state agencies about existing resources.

3. Structure the development of a service delivery system that includes parents as important planners, reviewers, and evaluators of goals, objectives and action plans.

All services to children with chronic illnesses should adopt a model of family-centered care with parent/professional collaboration at the policy level as well as in the design of individual services.

4. Coordinate and extend eligibility criteria to assure that all children with severe chronic illnesses qualify for medical support and other services.

Develop a service delivery plan for providing care to the high numbers of babies who are currently being born in Oregon with drug addictions, alcohol-related complications, and AIDS, as well as children who fit the definition of having a chronic illness but who are not covered by existing regulations.

5. Assure a support system that addresses the financial needs of all parents; with and without assets.

To move in this direction adopt the recommendations of the Governor's Commission on Health Care as well as other legislation that will provide support to chronically ill children and their families.

6. Assure that children with chronic illness are able to progress through school with

In addition, disseminate information about best educational models and practices for providing public school education to students with chronic illnesses through such activities as the Summer Institutes conducted by the Oregon De-

support such as home tutoring, assistance from school nurses, flexible school hours, and other adjustments to support their education.

partment of Education technical assistance packages, and local workshops. Finally, designate an educational specialist at the Oregon Department of Education to provide expertise to schools who have children with chronic illness.

7. Provide training that will qualify people to work with children who have chronic illnesses and their families.

To help accomplish this, the Department of Human Resources should extend training, particularly about resources and funding models, to staff in state agencies. The Oregon System of Higher Education should take responsibility for building competencies and requiring coursework about the needs of chronically ill children and their families as part of the teacher certification program in Oregon's colleges and universities. School districts, human service agencies, and medical service providers should adopt job descriptions that will enable them to hire personnel to fill new job roles.

Children who suffer from severe chronic illness are a neglected group in our society. Their suffering, the heavy burdens they and their families bear, the human resources lost to us all are matters largely unknown to the general public. Awareness of a particular chronic disease may occasionally be heightened briefly by efforts of a voluntary group to raise money on behalf of children with "its disease." But interest is fleeting. Chronically ill children live out their lives in a twilight zone of public understanding. As a consequence, our nation, often attentive to the problems of children and families, has lagged grievously in its response to the urgent needs of children with long-term health conditions.

Hobbs, Perrin & Ireys (1985)

I. Introduction

Prior to the early 1970s, Oregon children with severe health needs were cared for in pediatric hospitals, Providence Children's Nursing Center, or simply did not survive. The public educational system had not been asked to address the complex needs of this population. During the mid-1970s, children with severe health needs began to request services in Oregon's communities. There were few models upon which to rely and few precedents to follow.

Between 1978 and 1987 several classroom programs were developed in Multnomah and Washington counties. In 1978, Providence Child Center and the Regional Program for Physically Handicapped and Chronically Ill children, through Portland Public Schools, jointly sponsored an educational/day care program for ten multihandicapped children with severe medical needs at Providence. In 1981-82 a primary site was opened at Holladay Center in Portland to serve 7 more "medically-at-risk" students. In 1982-83 a second preschool site was opened at Children's Programs of Good Samaritan Hospital in Portland. This site served 10 additional preschoolers. The classroom was later moved to the Child Development and Rehabilitation Center of the University of Oregon Health Sciences University in Portland. In 1986-87 a primary classroom was opened by the Washington County Education Service District for 8 students from that county. In 1987-88 the Multnomah Education Service District opened two classrooms for primary age students of East Multnomah County.

Parents of students in these classrooms met informally for a number of years as Parents of Medically Impaired Children and, in 1984, were the nucleus for the formation of the Association for Severely Other Health Impaired Children (SOHI). A contingent of these parents appeared before the Oregon Educational Coordinating Commission hearings in July of 1984 to urge the commission to add a new category to its list of state-supported regional special education programs for children with severe health needs. Due to their advocacy, the category was added to the O.E.C.C. recommendations but was dropped from the list when the recommendations were considered by the Oregon Legislature. The primary reason for not including the new category was lack of information about the prevalence of such students and the costs to provide appropriate services to meet their needs.

Thus, in 1985 Providence Child Center was awarded $200,000 from the Major Awards Program of Gulf+Western Foundation of New York to establish a framework for providing more appropriate educational services for students with severe health needs in Oregon. One of the primary objectives of the "PROMISE Project" was to identify chronically ill infants and children throughout Oregon.

In 1986, the SOHI parent and advocacy group coordinated efforts with a Task Force organized by the Oregon Department of Education to present demographic information about children with chronic illnesses to the Legislature and, again, advocate for services. As a result of these efforts a Budget Note was inserted in the Department of Education 1987-89 budget that required the formation of a Steering Committee on Children with Chronic Illness and Their Families. The Oregon Legislature assigned responsibility for managing the Committee to the Oregon Department of Education.

The Steering Committee on Children with Chronic Illness and Their Families has been meeting regularly in response to the Legislative directive and has

begun work on a state plan for providing services. The members of the committee have developed a definition of the population of children who have chronic illnesses. They have also identified the primary needs of children with chronic illness and their families and have made recommendations about how those needs can best be met. During their last meeting of 1988 members recommended that the Department of Human Resources become the lead agency for coordinating continued efforts to develop a state plan and for providing information about existing services to children with chronic illness and their families.

This report examines chronic illness, the numbers of children in Oregon who fall under the definition of chronic illness, the various agencies that currently provide services, the results of a parent survey conducted in 1988, and issues that are getting national attention.

a. Definition of Chronically Ill

Many terms are commonly used to refer to children who are chronically ill. Some agencies or projects write about children who are "medically fragile", others to children who are "severely health impaired". Some projects focus on children who are "technology dependent" referring to a need for technological devices to maintain bodily functions. In this report "chronic illness" is used to encompass all these terms.

The definition of severe health impairments or chronic illness used by the Steering Committee on Children with Chronic Illness in Oregon states that it is a condition in which:

> *"... the absence of immediate health-related special skilled care threatens the life or health of the child and the child requires a medical protocol to ensure his or her safety; and there is no foreseeable end to this condition."*

A definition of severe chronic illness includes several features including a need for medical technologies, the separation of severe and mild conditions, and an emphasis on the chronic nature of the condition. These features are described below:

Need for Medical Technologies

Definitions cite the need for medical technologies to avoid death or further disabilities. A child may need a gastrostomy tube to eat or a tracheostomy tube to breathe. Some children require surgery to help correct arthritic conditions or to slow the effects of weakening muscles. Children may need chemotherapy for leukemia, oxygen for asthma attacks, or a blood-clotting agent and transfusions for hemophilia. Besides hospitalization, chronically ill children may also need medical procedures from nursing staff or trained personnel in the [illegible] maintenance of bodily functions. Children with spina bifida may need daily catheterization to remove urine from their bladder because their nervous system is not relaying signals to urinate; and children with renal disease may frequently require kidney dialysis.

Mild versus Severe Conditions

Most definitions discriminate between mild and severe conditions. For example, between 3 and 5 percent of all children are estimated to have asthma (Hobbs, 1985). Children with mild asthma may have some restrictions on the activities in which they engage or their environments and may benefit from medication that helps to open airways. However, about 5 to 10 percent of this group have a severe condition of asthma which regularly and significantly interferes with their activities.

Chronic Nature

Most childhood illnesses are of short duration. A child may be very ill with mumps, measles, or whooping cough but when the illness is over there are usually no further complications. Children with chronic illness have a condition that, although it may improve from time to time, does not go away. For example, a child with cystic fibrosis must have rest and the application of procedures to help drain the lungs, in order to participate in community activities or school. And, over time, if a schedule of activities is tiring and the child does not take a sufficient break to recover from fatigue, the condition may worsen until the child is forced to stop all activities to recover.

Respiratory Conditions. Asthma is a lung disease that results in impaired lung capacity. There are medications to help attacks, and immunotherapy to help reduce sensitivity. Cystic fibrosis is another respiratory condition. It causes major lung disease and lung infections.

Nervous System and Sensory Organs. These include deafness, vision impairments, and speech disturbances, and conditions such as seizure disorders and cerebral palsy.

Genito-urinary System. End-stage renal disease affects the kidneys and has no known prevention. Kidney failure can presently be treated by kidney transplants or by dialysis.

Endocrine System. Juvenile-onset diabetes is caused by insufficient secretion of insulin by the pancreas. Exercise, diet and insulin must be precisely controlled and children must often be given urine tests and insulin shots several times a day to monitor and control sugar levels.

Gastrointestinal System. Chron's disease or ulcerative colitis.

Musculoskeletal and Connective Tissue. Muscular dystrophy is a progressive increase in the weakness of muscles which often leads to death at about age twenty as the result of suffocation because the lung muscles cease functioning.

Congenital Anomalies. Congenital heart diseases include a variety of anomalies of the heart. Some are fatal, others can be corrected through surgery although the children are often at risk of serious infections and associated heart and lung problems. There are also craniofacial anomalies such as cleft palate, openings in the jaw, mouth, or other facial anomalies. These are often accompanied by a tendency for middle-ear infections, hearing loss, and speech impairments.

Immunological. Leukemia is the most common form of cancer among children. Although the survival rate is now very high, children with leukemia must undergo surgery and medication/chemotherapy treatments.

Other. An example is hemophilia, an absence of a blood clotting factor which results in uncontrollable bleeding. Most instances of hemophilia attacks are not the result of injury, but occur spontaneously. Bleeding often occurs in joints and can result in painful arthritis.

Figure 1. Major categories and examples of chronic illnesses.

In addition to fluctuations in the severity of a condition, many children with a severe chronic illness will regularly spend time in the hospital. The amount of time will depend on schedules for surgery and other remedial interventions, and on the severity of the condition. For example, infants and young children with spina bifida may have to undergo a series of surgical procedures, children with muscular dystrophy frequently have surgery to postpone the need to use wheelchairs, and children with hemophilia receive medications and transfusions on a regular basis.

Examples of Chronic Illnesses

There are literally hundreds of different chronic illnesses. The Steering Committee on Chronic Illness in Oregon organizes major types of conditions into nine categories (Figure 1). Although some chronically ill children have only one condition, others may have several. Children with chronic illnesses may also have another major handicapping condition such as a developmental disability, a visual or hearing impairment, or an orthopedic impairment. Children may also be called chronically ill if they have many types of conditions, none of which is significantly severe in itself, but taken together results in a severe and chronic impact on activities and the need for medical interventions.

b. Number of Children with Chronic Illnesses

Hobbs, Perrin & Ireys (1985) estimate that there are 62 million children under eighteen years old in the United States. Their data indicates that twenty percent or 1.5 million of these children have one of eleven "marker" conditions (juvenile onset diabetes, asthma, spina bifida, craniofacial anomalies, congenital heart diseases, leukemia, hemophilia, end-stage renal disease, sickle cell anemia, cystic fibrosis, muscular dystrophy). Because the marker conditions represent about 20% of the total chronic illnesses they estimate that 7.5 million children under eighteen years old have some kind of a health impairment. This is about 12% of the total population of children.

Prevalence Data in the United States

Hobbs further estimates that about 13% of this number or around 2% of the entire population of children have a severe health impairment. This figure means that one million children in the United States have a severe chronic illness that regularly interferes with activities on a daily basis (see Figure 2).

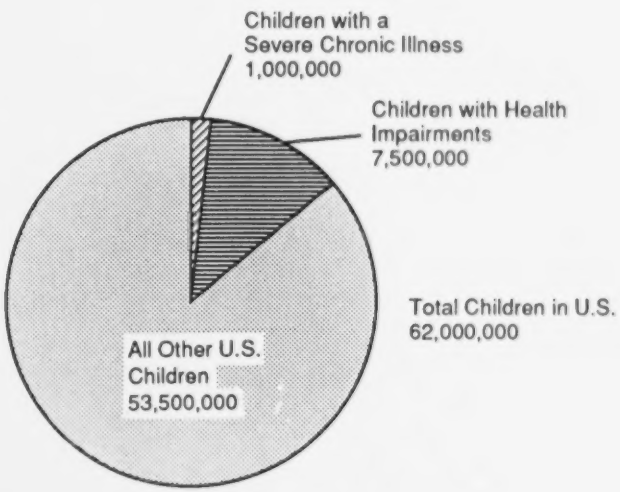

Figure 2. Estimated prevalence of children with severe chronic illness in the United States.

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Incidence Data in Oregon

There is no single agency which has primary responsibility for children who are chronically ill. As a result, no agency has complete information about the numbers of children in Oregon who meet the definition developed by the Steering Committee. However, in 1986, staff from the PROMISE Project administered a survey asking agencies and school districts to provide a count of the number of children with chronic illnesses. The results are shown, by region, in Figure 3.

Region 1: Eastern Oregon	55
Region 2: Central Oregon	71
Region 3: Southern Oregon	153
Region 4: Lower Willamette - Mid Coast	88
Region 5: Mid Willamette - North Coast	159
Region 6: Portland, NW Oregon	459
Portland Metropolitan	
Total:	985

Figure 3. Number of children with chronic illnesses identified by the PROMISE Project Providence Child Center in Portland in 1986.

c. Trends

There are several trends in the types of children who are medically fragile in the United States. Children who are chronically ill, as a whole, have more severe conditions, longer life spans and are more likely to participate in public school and other community programs. Of special note is the increasing number of babies being born with AIDS or children developing AIDS and the dramatic increase in the birth rate of drug-dependent babies.

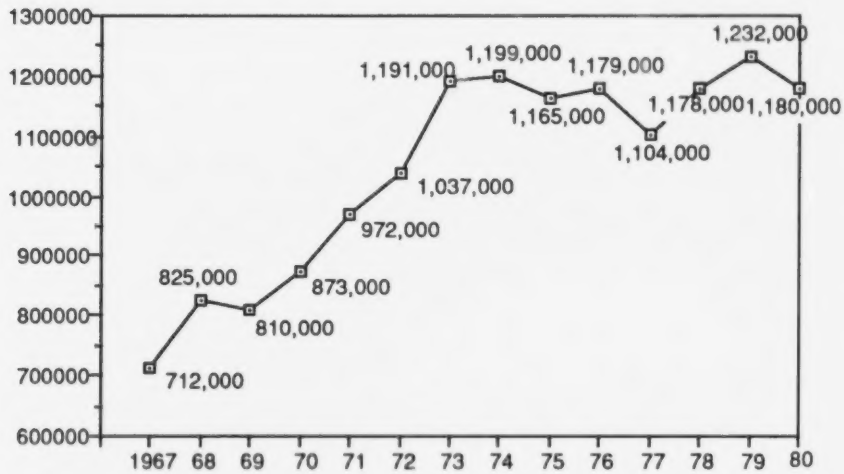


Figure 4. The number of children with chronic illnesses has doubled in a fifteen-year period of time.

More Severe Conditions

First, there have been many changes in the types of conditions that are considered severe chronic illnesses. However, the total number of babies who are born with chronic illnesses has not changed significantly. Because of advances in medical technologies, many babies who would have been born

handicapped are born without disabilities or are born with less severe disabilities than would have previously been the case.

At the same time, medical advances are saving many infants who previously would have died because of the severe nature of their health conditions. As a result, although the total number of births affected by chronic illnesses is about the same, the severity of the conditions is on the rise.

Longer Life Spans

National data indicates that the total number of children with severe health impairments has doubled in the last twenty years. Most of the increase is due to medical advances which have increased the life span of these children. About 80% of children with a chronic illness now survive childhood (Report on School-Age Children with Health Impairments, 1986).

Participation in Public School Education

There is a growing trend toward deinstitutionalization of children with severe disabilities. For example, Oregon Mental/Health guidelines stipulate that no additional children with disabilities may be placed at Fairview Training Center in Oregon. They also call for the community placement of all children and youth currently residing at the institution within the next two years. Professional services are being developed to support children and youth with all types of impairments at home, in foster care placements, in small group homes or in community nursing homes. The result of this trend is that increasing numbers of students who are severely medically fragile are residing in communities and will be attending educational programs in public schools.

Drug Dependent Babies

Although there is no statewide data, many hospitals in Oregon are recording a higher incidence of newborn babies who are drug-dependent. Children's Services Division figures indicate that 122 drug-addicted babies had been born in Multnomah County by August 1988. This is an increase of more than 50% from 1987 (The Oregonian, August 19, 1988).

Babies Born With AIDS

Because of the increasing incidence of adults affected with Acquired Immune Deficiency Syndrome (AIDS) there is a corresponding rise in the number of babies and children with this condition.

Although there is no statewide Oregon data on the ages of children with chronic illnesses, the trends in an increased number of infants with drug dependency and a higher incidence of premature infants who survive indicate that there is currently a great need for support of infants with chronic illnesses and that there will be a greater number of children needing specialized services through the school years. The data showing that more children with chronic illnesses are reaching adulthood does mean that there is a higher incidence for all ages.

"Families need a genuine support system in place. The system should focus on the family as the primary unit and be there as a resource when needed to meet their needs. We need to empower the families to exercise their choices about which services are important. We must not fall into the trap of funneling them into a system where the experts know what is best. The agency should not lead the family - the family should lead the agency."

Oregon Parent -
Association for Severely
Other Health Impaired Children

II. Parent Survey

There is an Oregon-based advocacy group which includes Oregon parents of chronically ill children. The Association for Severely Other Health Impaired Children (SOHI) is a group of concerned parents, educators and health professionals organized to improve the quality of life for severely other health impaired children and their families. They offer families support, vital information, and an opportunity to exchange ideas. They provide information about resources and advocate for developments that affect SOHI children. SOHI is funded exclusively by voluntary contributions and currently has about 200 parent members.

To help gather information about service needs and issues that are important for families, a survey was conducted in 1988. The survey was mailed in July to 200 SOHI parent members. About 35 of the surveys were returned because of an incorrect address. As a result surveys were able to reach about 165 SOHI members. Of the 165 people who received surveys, 52 or 31% were returned. Three surveys were from service providers and were not counted as parent results. One parent returned a survey for two children.

The following results summarize the forty-nine parents who responded. Although this is an acceptable rate of return for this type of survey, the results cannot be generalized to the entire parent group because of the relatively low numbers of participants. Nevertheless, the information provided by the parents who did respond may give some indications of the availability, accessibility, and financing of services in Oregon.

Surveys were organized into four sections. First, parents were asked for demographic information about location, age of child, and a description of the child's needs. The second section asked parents to identify their access to and need for a variety of services. Third, parents were asked to suggest changes that would improve service delivery. Finally, parents reported on the types of financial assistance that they have been receiving.

a. Demographic Information

Surveys were received from the following locations: Portland Area - 24, Willamette Valley - 16, Southern Oregon - 4, Coast - 1, and Eastern Oregon - 4. Two surveys did not include information on location in the state.

Ages of Children

Children represented in the survey ranged from two years to twenty-four years old. Two parents wrote about children who had died.

Age	*Number*
2-5	12
6-12	18
13-18	13
19-22	5
Died	2

Figure 5. Number of children with chronic illnesses by age group.

Conditions

Parents were not asked to specify handicapping conditions. Instead they were asked, "Briefly tell us about your child." Most parents described their child's

conditions. The conditions included uncontrolled seizures, brittle bone disease, cerebral palsy, ulcerative colitis, cancer, diabetes, scoliosis, fragile respiratory and digestive systems, asthma, rare chromosomal anomalies, Numan-Pick disease, Hypo-ventilation Syndrome, Herpes encephalitis, and multiple handicapping conditions. Many of these children have tracheostomies and/or gastrostomies and several were described by the parents as being totally dependent for all areas of care.

b. Service Needs

In the second section of the survey, parents were asked to describe 21 categories of services in terms of adequacy, accessibility, and funding.

Adequacy

Parents reported that services were adequate in the following five areas: Knowledgeable occupational/physical therapists (24), Hospital Care (22), Knowledgeable Doctors (21), Knowledgeable Dentists (21), and Parent Support Groups (20). There are two interesting trends in this information. First, the majority of the categories are medically related and may indicate that medical support is generally quite adequate. Second, satisfaction with services and need for particular services may be somewhat related to geographical location and school district. For example, some schools have school nurses and parents seem to feel that services are adequate. In other school districts there are no school nurses and parents report the need for services.

"I have to do all the case managing."

Oregon Parent Association for Severely Other Health Impaired Children

Accessibility

Participants indicated that many services were still needed. The eight categories of services that participants identified the most frequently were:

	Number	Percent
Access to information about funding sources and services	33	67
Information to help promote public awareness	22	49
Knowledgeable school staff	22	49
School nurses	20	41
A transition program	19	39
Medical care in the home	19	39

Figure 6. Parents indicated that they needed access to six categories of services.

Need for Funding

Although funding needs vary from family to family, four categories of funding needs were identified by many parents: 1) Special Equipment (47%), 2) Respite Care (45%), 3) Counseling/- Psychological (39%), and 4) Medical Care in the Home (37%). The complete results of this section of the survey are presented in Figure 8.

Support

Thirty-one parents responded to the question asking them to identify five service areas that are most important for the state to support in the next biennium. The two most frequently cited areas were Respite Care (74%) and Appropriate Public Schools (71%). Parents commented specifically about the need for teachers who are trained to serve medically fragile children in their

classrooms and administrators who are informed about the needs of medically fragile children.

	Number	Percent
Respite Care	23	74
Appropriate Public Schools	22	71
Access to Information	12	39
Transportation	10	32
Knowledgeable Occupational/ Physical Therapists	10	32
Transition Programs Between Agencies/Facilities	10	32

Figure 7. Areas that parents recommended for support during the next biennium.

Need Access	Need Financing	It is Adequate	Service
21	23	9	Respite Care
11	4	20	Parent Support Groups
16	14	19	Transportation to and from
12	14	23	Knowledgeable Occupational/ Physical Therapists
19	12	13	A Transition Program
33	6	9	Access to information about funding sources/services
16	2	21	Knowledgeable Doctors
15	3	21	Knowledgeable Dentists
17	7	16	Parent Education
17	8	17	Appropriate Public Schools
20	10	15	School Nurses
21	6	9	Sibling Support Groups
18	19	11	Counseling/Psychological Services for children with special needs and their families
19	18	7	Medical Care in the Home
17	23	10	Special Equipment
12	7	19	Diagnostic Evaluation
16	10	11	Out-of-Home Placement
5	4	22	Hospital Care
22	13	9	Information to provide public awareness (films, materials, workshops)
22	7	15	Knowledgeable School Staff
18	7	13	Case Coordination

Figure 8. Results of the Parent Survey.

c. Changes in the Service Delivery System

Eighteen parents wrote about their need for an improved service delivery system with an emphasis on coordination of services, a need for a single point of referral, and assistance of a single, designated case manager. Parents also wrote of the need for state funding of basic services such as medical care, in-home support, and equipment. The second area of concern was for appropriate school services with teachers trained to provide services to medically fragile students, access to school nurses, and informed administrators. The third major area of concern was funding for respite care. Parent responses are organized by category in Figure 9.

"The state affords us no option other than large congregate care facilities. Her medical needs are substantial... We believe that she could be cared for in a small community-based facility for a comparable cost and possibly at home."

Oregon Parent Association for Severely Other Health Impaired Children

"We need private insurance coverage, but can't get it because of our child's pre-existing condition. The cost (of care) is exorbitant."

Oregon Parent Association for Severely Other Health Impaired Children

Question: Based on your experience with your child who has special needs, what, if any changes would you suggest in the service delivery system?

System Changes
- Coordinated Services
- Case Management
- Funding for medical expenses

Family Support
- Entitlements
- Services based on needs of the individual
- Focus on prevention, not crisis intervention
- Respite Care

School
- Trained Bus Drivers
- Safe Classes
- Trained Staff
- Transition Services
- Well-Informed Administrators
- School Nurses
- More Adequate Funding

Figure 9. A list of needs for improving service delivery to chronically ill children and their families.

d. Sources of Funding

Insurance

The fourth section of the survey was designed to gather information about categories of insurance, medical, and other types of support parents are currently receiving. In the insurance category, most of the parents report that insurance is offered through work (28). Some parents purchase their own insurance, or receive public insurance through Medicare, Medicaid or Adult and Family Services. A few parents pay for each visit to the doctor. Sixteen parents reported that they have no insurance at all.

Please identify the category or categories of financial support that help you pay for services for your child.

Private Insurance

28 Offered through work
8 Privately purchased
4 Other

Public Insurance

11 Medicare
4 Medicaid
4 Other

No Insurance

7 Tried to get private insurance and did not qualify
5 Tried to get public insurance and was not eligible
4 Did not try to get insurance

Figure 10. Insurance status of participants.

In addition, 20 children have received services through Child Development and Rehabilitation Center, 13 through Shriner's Hospital, and six through Easter Seals.

Some financial support has been obtained through hospital programs, Regional Services from the Oregon Department of Education, the local Health Department, United Cerebral Palsy, and private care. Other financial support was received from Supplemental Security Income (17), Social Security (4), Oregon Family Support Services (3), and others including help from the parents, other family members, churches, or friends.

Costs

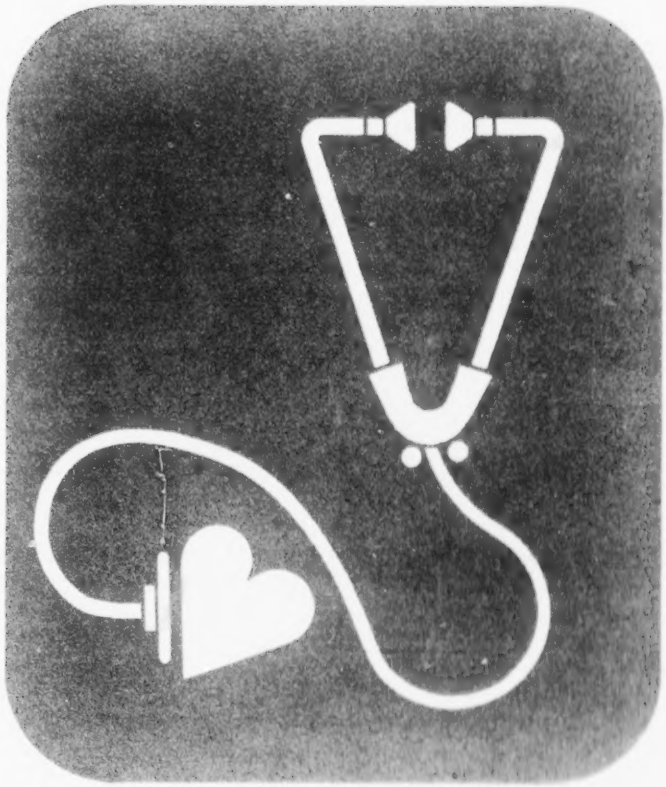
The last question in this section was concerned with the total cost a family pays for medical care, support services, special equipment, and other needs of their child. It is important to note that 17 parents (40% of the group that responded) paid between 11% and 25% of their total income to provide medical care for their child.

	Number	Percent
10% or less of income is spent	23	54
11% to 25%	17	39
more than 25%	3	7

Figure 11. Number of parents by percent of income spent on medical care for a chronically ill child.

e. Summary

The basic and consistent message from the parents who responded to this survey was that services are fragmented, medical costs are prohibitive, and schools are often unprepared to meet their child's medical needs. This results in families who are under considerable emotional and financial stress and, who, in some cases have to relinquish care of their child to financially and emotionally survive. In many cases financial assistance for medical costs, support services such as respite care or an in-home aid to assist with lifting, and coordinated case management would make significant differences in the lives of these children and their families.



[There are] substantial problems including: 1) overzealous ... workers who have unrealistic notions about [the] need for skilled nursing care, 2) case managers who perceive their responsibility as being to conserve agency resources, 3) irregular paychecks for support ... and difficulty in obtaining essential related services ... 4) unfortunate SSI and funding regulations that view in-home placement differently from institutional placement.

Oregon Parent -
Association for Severely
Other Health Impaired Children

III. State Agencies

Children with chronic illness and their families often receive services from several agencies. The following section describes the primary roles of state agencies which could provide support and services to families with children who are chronically ill. Agency representatives were interviewed, not only to obtain a description of their agency's role in providing services to chronically ill children and their families, but also to identify the most important service needs that must be addressed.

Oregon Department of Education (ODE)

The Department of Education is responsible for Oregon's public school programs including special education and the implementation of Public Law 99-457. ODE administers the development and implementation of Individualized Education Plans for children who are chronically ill and require an IEP in order to benefit from an education program. During 1990, the Department of Education will conduct a Summer Institute to disseminate information about chronically ill children, medical procedures, coordination of services within public schools, and transition planning. The Summer Institute will provide two weeks of intensive training for special education teachers and administrators. In 1990, six workshops, one in each of the state's six regions, will be conducted to review the content of the Summer Institute and to provide further assistance to participants.

Children's Services Division (CSD)

A primary role of the Children's Service Division is to provide medical foster care to children with severe health impairments who cannot live with their natural parents. As guardian, CSD must assure that children receive appropriate care, medical services, special education, and entitlements such as medical assistance through Adult and Family Services, supplemental security income through Social Security, and vocational training through Vocational Rehabilitation Division. Appropriate care givers must be located, certified, and trained to provide care. A secondary role of CSD is to assist parents who are caring for a child who receives Exceptional Care Services funded through Adult and the Family Services medical assistance program.

Adult and Family Services (AFS)

Children who have a long-term disability may be eligible for cash assistance from SSI as a disabled child. Anyone who receives SSI is automatically eligible for medical assistance provided through the Medicaid program. Medical assistance is generally as comprehensive as coverage offered through most insurance companies and includes payments for hospitals, physicians, pharmacy products, and physical therapy. As with insurance companies there are limits on how much service can be given. For example, there are unlimited office visits to see physicians but only 18 days in the hospital are covered.

Federal law now allows reimbursements for health services offered as related services in schools and AFS is currently working with schools to develop policies. In addition to SSI eligibility, if children are in families who receive Aid to Dependent Children benefits they are entitled to the cash subsistence payments and food stamp payments through AFS, and will be eligible for a medical card.

Families whose income is above the poverty level will, if they qualify for assistance, pay part of the medical costs. AFS records indicate that 35% of the school children in Oregon are Medicaid eligible.

Finally, AFS offers preventive services including screening, diagnosis, and treatment for medical and dental needs of all children birth through 21 who

have a medical card. AFS also will pay for prenatal care of those who meet minimal eligibility requirements.

Oregon Mental Health Division (MHD)

Children who are chronically ill and also have a developmental disability qualify for services through the Oregon Mental Health Division. Developmental disabilities include neurological impairments such as epilepsy, cerebral palsy, mental retardation, autism, or accident-related brain damage that occurs before age 22. The available services include case management through County Mental Health Program, Early Intervention services, transition planning for adult services, and family support. When necessary, residential programs may also be provided.

Vocational Rehabilitation Division (VRD)

The Vocational Rehabilitation Division serves high school students and adults who have disabilities. VRD staff can assist with such services as counseling and guidance, job development, job placement, training, and other related services such as transportation, work clothes, tools, or occupational licenses. People with chronic illnesses may need support in obtaining and maintaining a job. VRD estimates that only a limited number of high-school students with chronic illnesses are currently involved in VRD services.

Development and Rehabilitation Center (CDRC)

A division of the Oregon Health Sciences University and administrator for the state's Title V services for children with special health needs, CDRC seeks to assure that persons with physical handicaps and developmentally disabling conditions are identified and assured ready access to coordinated services. In addition to financial support for in-patient services to eligible, indigent children, CDRC conducts programs of clinical service, education, research, and development. Staffed Child Development and Rehabilitation Centers are maintained in Portland, Eugene, and Medford. Clinics are also held in nine other Oregon communities.

CDRC offers diagnostic and consultation services for any child or young adult suspected of having a wide variety of handicapping conditions (see Figure 12). At the present time CDRC does not cover some chronic illnesses such as leukemia, cancer, and AIDS.

Heart Diseases
Counseling for Genetic Disorders
Abnormalities of the Head and Face
Chronic orthopedic disorders
Myelomeningocele and hydrocephalus
Metabolic Abnormalities
Developmental Disabilities/Cerebral Palsy
Hemophilia
Muscular Dystrophy
Rehabilitation of Burns
Traumatic Paraplegia and Quadriplegia
Rubella

Figure 12. Chronic illnesses that meet eligibility requirements of CDRC.

Senior Services Division (SSD)

Senior Services Division primarily provides coordinated services to elderly people and to disabled people over 18 years of age. The agency also operates

a section which licenses and monitors nursing homes in Oregon, sets rates for SSD nursing facilities, and case manages children who live in nursing homes.

About 100 medically fragile children are served in SSD nursing facilities. To be eligible for an SSD-paid nursing facility, children must meet existing criteria for Medicaid eligibility, and must require services that can only be delivered in a nursing facility setting. Eligibility is determined by Senior Services Division in a case planning conference involving representatives from the local school system, the Mental Health Division, Senior Services Division, and involved service providers. SSD also coordinates a DHR interagency Exceptional Care Committee which authorizes payments for Medicaid services for eligible children with unusually high care costs.

Providence Child Center

Providence Child Center is one of 18 private, non-profit institutions sponsored by the Sisters of Providence. The Child Center's programs (Montessori School and extended day care, Emily School, and Children's Nursing Center) serve approximately 250 children daily. The Children's Nursing Center is Oregon's only 24-hour, skilled pediatric nursing facility for chronically ill/medically fragile children. The facility serves 54 infants and young children from all over Oregon. In addition, Providence Child Center provides technical assistance and outreach services to chronically ill children and their families throughout Oregon.

Health Division

The Mission of the Health Division is to protect, preserve and promote the health of the citizens of Oregon. One key method for accomplishing this goal is to work as a partner with local government in planning, developing and providing public health services. While the Health Division provides technical assistance and administers some of the funding, direct child health care services are provided by local health departments. These services include well child care, acute child health care, and follow-up of high risk children (including those with chronic illness). In an effort to further promote the early identification of chronically ill children and ensure that appropriate services are offered to their families, the Health Division has proposed that a statewide, high risk infant screening and follow-up system be established.

Governor's Commission on Health Care

One of the tasks of the Governor's Commission on Health Care for this biennium is to develop recommendations for providing adequate health care for children with chronic illness. The Commission is examining issues related to income requirements for eligibility, the creation of an insurance pool for people who have not been able to obtain insurance coverage, and a reworking of the waiver system for children with chronic illness in Oregon.

"Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on a child's health ... a child is dependent upon his or her mother and other family members not only for the physical necessities of life ... but also for the emotional support and intellectual stimulation needed for healthy growth and development.... The family is not only the principal influence upon a child's development, it is also the intermediary between the child and the outside world, including the health care system...."

Schorr, Chair of the Select Panel
for the Promotion of Child Health,
The Family-Centered Care for Children with
Special Health Care Needs (1987).

IV. Recommendations

In Oregon, there are few organized services for children with chronic illnesses and their families. Parents who responded to a survey for this report and personnel from representative agencies frequently described the lack of formal case management, the financial hardships of families, the general lack of knowledge about existing services within state agencies, and the shortage of teachers and other personnel with training to help support children with chronic illness in community settings. As a result of the information gathered and presented in this report, this section includes seven recommendations which can immediately be implemented to continue the process of building a state plan that will adequately assist children with chronic illness and their families in Oregon. The seven areas around which recommendations are made include:

1. The continued development of a State Plan
2. Formal case management
3. Normal patterns of family living
4. Eligibility for services
5. Financial support
6. Public school education
7. Training

1. Continued Development of a State Plan

"We need to develop a statement of values that shows families are valued and that we acknowledge their trauma and their need for support. The state then becomes the avenue for executing this value."

George Hall
Oregon Mental Health Division

Many of the parents and professionals interviewed for this report commented that there needs to be an acknowledgment of the value of chronically ill children and a commitment to supporting these children and their families. Some state agency staff suggested the need for a mission statement that could be then used as a guide for structuring a state plan for providing services.

Parents, professionals, and other advocates have also strongly recommended the development of a state plan for providing services to chronically ill children and their families. Foremost, they feel that the plan needs a statement of values and a philosophy from which services are designed. Above all the philosophy should articulate the value of children who have chronic illnesses, the rights of families to assistance, and the rights of children to live in families and participate in communities. The state plan must include goals and objectives, a delineation of agency responsibilities, plans of action with tasks and timelines for accomplishing goals and objectives, and a monitoring system for evaluating progress toward implementing the state plan. The specific needs that have been identified and discussed in this section have come from the work of the Steering Committee, of the SOHI advocacy group, and the suggestions of state agency representatives.

Recommendation: Continue the mandate for a Commission on Chronically Ill Children and Their Families.

In addition to providing a forum for coordinating resources, a primary task of the Steering Committee should be the continued development of a State Plan that specifies the adoption of a mission statement, goals, objectives, timelines, and responsibilities.

2. Formal Case Management

In Oregon, at the present time, only those parents whose children also have a developmental disability have access to a case manager through the Oregon Mental Health Division. Without formal case management, parents have had to take primary responsibility for identifying resources and coordinating services. These services may include the Health Division, Adult and Family Services, Senior Services Division, Child Development and Rehabilitation Center, Children's Services Division, education, and a variety of medical and related service providers.

"I knocked on many doors and made hundreds of calls and finally came to the realization that the attitude here is "You had the child - she's your problem" .... We need knowledgeable and caring social workers who [provide] services to all."

Oregon Parent - Association for Severely Other Health Impaired Children

Because there are multiple contacts, many parents waste time trying to learn how to access the supports that may be available. Most parents and representatives from state agencies believe that there should be a single point of access for inquiring about support for chronically ill children and their families. They believe that offices should be available at the local level where parents can readily meet service coordinators to learn about available resources. Parents not only need access to information about services that are available, but also eligibility requirements and procedures for receiving services. Parents may also need assistance in defining the type of support that is needed for their family and may need assistance in accessing that support.

In addition, case management services can assist parents in obtaining the most appropriate and cost-effective equipment and services. There are financial limits on the total amount of money that can be spent through insurance policies and medical interventions and equipment for chronically ill children can be very expensive. To use money wisely it is important for parents to have access to information that will allow them to make informed choices. Case management services could provide an avenue for assisting parents with these choices.

Recommendation: Designate and fund a single agency through which parents can access information about services and can access case management of services for children with chronic illnesses.

To begin this process, move responsibility for facilitating the continued development of a State Plan for chronically ill children and their families from the Oregon Department of Education to the Department of Human Resources. These responsibilities will require funding for at least a full time staff person, either FTE or contracted, and a secretarial position to coordinate the efforts of the Steering Committee and to provide information to consumers and state agencies about existing resources.

3. Develop Models that Promote Normal Patterns of Family

"An optimal situation would be a formula that attaches value to a child's special needs, and then provides parents with a check that allows them to arrange ... optimal care."

Oregon Parent Association for Severely Other Health Impaired Children

While the conditions of children with severe health impairments are markedly different, the effects on children and families have many similarities. Children who have serious health impairments must often be hospitalized to avoid or recover from crisis situations or to receive medical interventions. These interventions are often uncomfortable, frequently painful, and can be very intrusive. The treatments may not only be costly but often have associated additional expenses such as travel, lodging, and purchase of medications that pose a real financial drain on the family. Entitlement regulations and insurance may often restrictive, inconsistent, and inflexible and may not cover many of the costs of medical care and associated expenses.

As a result there are tremendous stresses on children who sometimes do not want to continue treatments and their families who feel helpless to provide relief, who are financially taxed, and emotionally and physically drained. Principal concerns for supporting and strengthening the family unit focus on financial coverage for medical and related services, utilizing parents as planners in all aspects of services, and developing approaches to funding that support children with chronic illnesses in communities with their families or with other community caregivers.

Funding Families

A family can be a child's natural parents, adoptive parents, or "parents" in other home placements such as foster care. As many professionals now recognize, families are the single most important source of support for chronically ill children. Staff from service agencies, medical centers, and schools change throughout the day and from month to month or year to year. On the other hand, parents provide whatever level of personal care is required whether it is dressing, feeding, toileting, or cleansing. They may be responsible for providing therapies, giving medications, and using medical equipment such as heart

monitors at home. They may provide transportation to school, to medical centers or hospitals, to favorite community events.

To help preserve the family unit and support its efforts, many professionals now feel that it is important to change the focus of service from the child to the family. Instead of developing plans that center only on the health needs of child, they are advocating that service agencies and others consider the impact of a plan on the entire family.

Many agencies admit that in Oregon parents must act desperately if they are to receive financial help for a chronically ill child. They must be willing to call a crisis line or give the child to a Foster Care or Nursing Home Placement. To eliminate this unfortunate fact, members of the Steering Committee on Children with Chronic Illness and Their Families recommend that services be structured so that they 1) provide comparative financial support for families who want to keep their child at home and 2) provide options for the ways in which support can be received.

Historically, the MHD has provided case management and financial support to cover the costs of children who are institutionalized or placed in group homes or other residential facilities. The agency has not provided this support to parents who wish to keep their children at home. During the fall of 1988, this policy was somewhat changed as several county Mental Health Programs were awarded block grants with wide flexibility in how children with developmental disabilities could be supported at home with their families. The philosophy behind this pilot project is: "When agencies become involved with families they should support the families' natural sources of support and help to build new connections to existing community resources. When natural sources of support cannot meet particular needs of families, specialized services should be made available." (From Request for Proposals issued by the Oregon DD Council and the Mental Health Division). This approach to funding may be the new trend in providing appropriate, flexible, and individualized support to chronically ill children and their families.

Coverage At Home

Currently, most hospitals and medical centers try to accommodate children at home as much as possible. For example, children may enter a hospital and return home several times during a course of treatment to minimize the amount of time spent away from home. Parents are being trained to use medical protocols and to operate monitoring devices or equipment used as part of a medical treatment program at home. Systems of financial support frequently penalize policy holders when care is provided outside the hospital. It is important to structure these services so that at-home care can be provided by family members and others without loss of needed services, or insurance penalties.

Parents As Planners

Traditionally professionals have been in control of services. They "... provided care, made the decisions, and controlled the flow of information to families." (Family-Centered Care for Children with Special Health Care Needs, 1987). Public Law 99-457 specifically states that parents have a right to basic information and to participation in the decision-making process. Parents of chronically ill children need to participate not only in decision-making and planning at schools, but also with medical and hospital staff, with community service programs, and at the policy-making levels of agencies and state government.

There are many reasons for this involvement. First, parents know their child better than anyone and have a valuable perspective to offer professionals in designing programs that will be effective and that can be implemented at home.

Parents also know the capabilities of their family situations and have strongly stated their desire to actively participate in all aspects of decision-making for their child.

The Family-Centered Planning Program at the Kennedy Institute for Handicapped Children in Baltimore, Maryland employs a model for parent involvement that includes the following features:

> **"Visits are made in the family home or preferred location at a time convenient to them [the parents].**
>
> **Staff complete a needs assessment based on the parents' concerns, desires, and needs.**
>
> **Parents are the key to the development of the annual service plan. They determine who will attend, where, and when it will be held, and what role they want to assume, (i.e. chair or active participant).**
>
> **The service plan is comprehensive and addresses all areas of need (i.e., services to the child, family supports, financial assistance, recreation, and emotional needs).**
>
> **When requested, staff are available to assist the family in enhancing their individual skills as their child's advocate and coordinator."**
>
> *Family-Centered Care for Children with Special Health Care Needs (1987).*

Shelton, Jeppson, and Johnson (1987) in a Family-Centered Care for Children with Special Health Care Needs recommend a family-oriented model that can build on the knowledge of the parents: In order to efficiently obtain accurate information about the needs of a child and a child's family as well as the capabilities of the family to provide health care and other support, it is important that the family members be involved in all aspects of planning. With this approach parents attend all assessments and help express their child's responses to questions, or even to help to administer test items. When planning occurs, all members of the planning team are present so there is no need for multiple assessments, parents need to answer questions only once, and parents are present for a discussion of the results. Parents help to identify their child's weaknesses and strengths, and participate in all discussions. To meet a family's needs, recommendations for services are focused on the parent's priorities.

Recommendation: Structure the development of a service delivery system that includes parents as important planners, reviewers, and evaluators of goals, objectives, and action plans.

All services to children with chronic illnesses should adopt a model of family-centered care with parent/professional collaboration at the policy level as well as in the design of individual services.

4. Eligibility for Services

Each agency that provides services has guidelines defining specific handicapping conditions for which they are responsible. For example, the State Mental Health Division, Developmental Disabilities Program Office, is responsible for case management of children with developmental disabilities; the Child Development Rehabilitation Center offers diagnostic services to children who have any of twelve specific conditions. Children's Services Division and Senior Services Division work together to set rates and provide residential care to children with health care needs who may be cared for in a nursing home. Staff

"[We must] expand categories to include all severe conditions. Oregon is one of the few states that does not automatically find children with leukemia and other malignancies eligible for services."

Dr. Al Browder
Child Development and Rehabilitation Center

at county Health Departments assess and refer infants and children with specific health needs.

Although many children receive health and other services through these agencies, there are major gaps. Children with cancer or AIDS do not currently fit within the definitions of any of the state agencies. Children with congenital heart conditions qualify for Medicaid, those with lung conditions do not. For this reason, representatives of several agencies recommended that instead of tying eligibility requirements to specific health conditions, the requirements be generally expanded to include any "high risk" infant or child.

In addition, current trends in Oregon show an alarming increase in the number of infants who are born with a drug addiction, alcohol-related complications, or AIDS. These babies are being moved into the human services delivery system at birth. Resources must be provided and coordinated, not only at birth, but also for preschool and school-age years. Additionally, a strong program of information and prenatal care could prevent many cases of these conditions.

Recommendation: Coordinate and extend eligibility criteria to assure that all children with severe chronic illnesses qualify for medical support and other services.

Develop a service delivery plan for providing care to the high numbers of babies who are currently being born in Oregon with drug addictions, alcohol-related complications, and AIDS, as well as children who fit the definition of having a chronic illness but who are not covered by existing regulations.

5. Financial Support

"Ill children can bankrupt any family. Even if I was able to work, I couldn't, I was the care provider. We have always had 80% insurance coverage. Medical bills for one year could amount to $160,000. Often times we were left in a position where we owed 20% of the uninsured balance. Oregon is the only place we have lived where there is no financial medical help for those who work."

Oregon Parent - Association for Severely Other Health Impaired Children

Oregon is one of the lowest-funded states in providing financial support to chronically ill children and their families. Many states automatically have waivers for Medicaid available to chronically ill children. In addition, Oregon consistently funds programs that affect children with chronic illnesses below the allowable federal cap.

Many parents and professionals report that the present system of financial coverage encourages families to act in very dramatic ways in order to obtain support. Children are supported if they are institutionalized or placed out of their natural homes; a mother can obtain a medical card if the father divorces her and leaves her with no or very little income; families may obtain support if they sell homes or other assets and spend their existing money. Because of these and other gaps in the health care system, a Commission on Health Care is studying the health care needs of citizens in Oregon and will be making recommendations in support of legislation that will help alleviate those needs. Three of the recommendations pertain specifically to the families of children who are chronically ill.

The Governor's Commission on Health Care

Most families are covered by private insurance programs for at least a portion of their child's medical expenses. If a family has no assets and low-income eligibility criteria they may qualify for public insurance. If a family does not have access to private or public insurance, they must meet medical expenses themselves and the expenses may bankrupt them. Research indicates that there are additional financial hardships that are common in families with a chronically ill child. A two-income family may find that one parent must quit a job to provide home care. Because of the high cost of medical care, even with insurance families lose assets by incurring medical expenses.

The costs of providing adequate care for children with chronic illnesses are astounding. The average costs for health care to the typical family in Oregon do not begin to approach the high costs associated with medical care for children

with chronic illnesses. In addition, to medical care, there are tangential expenses that may include costly medications, transportation over long distances, lodging for family members when a child must spend the night away from home, equipment, physical therapy, speech therapy, counseling, respite care, and special diets. A sampling of the average costs of care in 1985 for some of the conditions that make up chronic illness are presented in figure 14.

Condition	Procedure	Average Cost
Cystic Fibrosis	Hospitalization	$11,745
	Physical therapy	1,610
	Prescription drugs	1,509
Kidney Disease	Hospitalization	24,524
	Physician costs	4,205
	Related costs	8,874
	Dialysis equipment	3,000
	Home dialysis supplies	7,800
Leukemia	Treatment	1,959
	Nonmedical costs	1,450
Congenital	Cost of care 1st year	13,000
Heart Disease	As of 1980	
Spina Bifida	Cost of care birth to age two	70,000
	Cost of care birth to three wks old	6,500
Asthma	Range of costs over	800 to
	3 year period	13,407
Hemophilia	Medical care (1978)	8,071
	Replacement factor	7,039 to 9,673

Figure 14. Examples of costs for medical services, adapted from information presented in Hobbs, Perrin and Ireys (1985).

High-Risk Insurance Pool

The Commission is recommending that a high-risk insurance pool be made available to all Oregonians who do not otherwise qualify for insurance benefits. Families of children with chronic illnesses would be able to purchase insurance covering conditions that may have been excluded through other insurance programs because of a prior condition, because expenditure ceilings have been met, or because of some other exclusionary policy in the coverage. Families would have to purchase the insurance and the cost of the premium would be limited to no more than 150% above the average price of regular insurance. There would, however, be a six-month waiting period before a person would be eligible for this program.

Income Eligibility

Eligibility for Medicaid benefits would be expanded to the federal government guidelines. These guidelines stipulate that for children up to one year old, parents' income cannot exceed 185% of the poverty level; for children over one year old up to eight years old, income cannot exceed 100% of the poverty level. Only income, not assets would be counted. As a result, parents with a home or other assets do not have to spend them down before applying for public financial coverage.

Federal Waivers

The Commission will recommend federal waivers from normal Medicaid rules for children with health needs. Because the members of the Commission believe it will save money, they will also suggest that Medicaid monies be made available to purchase insurance from the high-risk insurance pool.

Recommendation: Assure a support system that addresses the financial needs of all parents; with and without assets.

To move in this direction adopt the recommendations of the Governor's Commission on Health Care as well as other legislation that will provide support to chronically ill children and their families.

6. Public School Education

"[We need] more effective ways to safely mainstream chronically ill children into the educational system."

Dr. Grant Higginson
Oregon Health Division

Most chronically ill children can safely attend public schools if staff are available to implement a specific medical procedure should it be necessary. Generally procedures are relatively simple such as administering a decongestant for a light asthma attack. More involved procedures may include knowing how to assist with intermittent catheterization, replacing a tracheostomy tube if it becomes dislodged, or administering CPR if a child should stop breathing.

The results of court rulings on medical procedures in educational programs indicate that schools are expected to make provisions for medical procedures that can be implemented by a school nurse. Procedure manuals and guidelines that provide models and detailed descriptions of health-care procedures have been developed in Oregon and through several national projects.

Flexibility

Public Law 99-457 mandates that all children have a right to education services through a public school program in a least restrictive environment. Most children with special needs in Oregon receive educational services through the school district's special education program. They are often educated in special education classrooms with Individualized Education Plans that incorporate alternative curriculum and instructional methods. For example, they may be taught to dress or feed themselves, to ride a bus, or to respond to specific directions. Some chronically ill children, in particular those with developmental disabilities, may benefit from this approach.

However, most chronically ill children do not require changes in curriculum or teaching methods. Instead, they need flexibility in attendance requirements, alternatives for how and when instruction is delivered, and medical support that will keep them safe while they are in school. Meeting these needs is currently very difficult for school districts. Although some large school districts have access to special therapy equipment and trained staff, many children continue to experience barriers to safe attendance. Schools may not have school nurses and teachers may not know how to implement medical protocols. In addition, support services such as special transportation, physical and speech therapy, counseling, or transition planning may be unavailable. The school may not have flexible attendance requirements that allow for prolonged absences due to medical conditions.

Access to School Nurses

The school nurse is a natural source of medical support for chronically ill children. They have the knowledge to develop emergency protocols and to implement medical procedures for those children requiring them. By working with teachers and paraprofessionals, school nurses could provide the training that would help meet safety requirements of children with chronic illnesses. Twenty years ago almost all schools had school nurses available on-site. A recent survey of 107 school districts throughout Oregon indicated that about 45% percent of schools employed school nurses. The nurses worked sometimes only a half day in a school, and there frequently was a nurse:student ratio of one nurse to two or three thousand students and occasionally to more than 5,000 students. This decline in the number of medical personnel in the school system

is supported by national data and is attributed to budget cutting brought about by a decrease in childhood contagious illnesses such as measles, mumps, whooping cough, and polio. Without an adequate supply of school nurses, necessary training and interventions will not be available to schools throughout Oregon.

Teacher and Administrator Training

A state survey conducted in Kansas (Mulligan-Ault, Guess, Sturth, & Thompson, 1988) documented that teachers, paraprofessionals, and school nurses shared the responsibilities of providing health care to chronically ill children in public schools. Their survey showed that, with proper training and qualified supervision, teachers are able to perform many health care procedures in the classroom.

Currently, the Oregon Department of Education is planning to conduct a two-week intensive Summer Institute for teachers who work with chronically ill students at the elementary, junior high and high school levels. The Summer Institute will occur during the summer of 1990 and will address health conditions, needs of families and children, procedures for providing health care and related services in the school, and health care. Data from previous Summer Institutes conducted in other areas has consistently demonstrated that this approach to inservice training is excellent for disseminating information and that teachers return to their school districts and successfully implement program changes and conduct training with other teacher groups.

In addition to conducting Summer Institutes, the Oregon Department of Education employs educational specialists in areas such as Autism, Hearing Impaired, Vision Impaired, and Deaf-Blind. SOHI, the parent advocacy group, recommended in 1984 that a specialist with expertise in the field of chronic illnesses be added to ODE to coordinate training efforts and provide information to teachers and administrators. At that time, the recommendation was not adopted due to a lack of information about the numbers of children in Oregon with severe chronic illnesses. A specialist who is knowledgeable about the unique health needs of chronically ill children and the educational models that are being developed to provide appropriate education could provide much needed direction in helping schools develop programs that are responsive to the needs of students with chronic illness and their families.

Funding

The primary debate about health care for children with chronic illnesses in school focuses on costs and the burden of providing care. No federal or state guidelines have been written to delineate the legal and financial responsibilities associated with at-school health care and related services. Although many court rulings have supported parents advocating for school-supported health practices that are required during the day such as clean, intermittent catheterization, the use of ventilators or even an air-conditioned room, a court also ruled that schools did not have to supply care when there were excessive costs and burdens to the school (Desel v. Bd. of Ed. EHLR 557:335 (N.D.N.Y. 1986). In Oregon, Adult and Family Services (AFS) has begun to meet with school districts to identify ways in which the organizations can work together to fund health-related interventions. Nevertheless, because the issues of responsibility are complex and the costs are substantial, funding of medically related services by schools will probably continue to be debated in national and state courts for some time.

Recommendation: Assure that children with chronic illness are able to progress through school with support such as home tutoring, assistance from school nurses, flexible school hours, and other adjustments to support their education.

In addition, disseminate information about best educational models and practices for providing public school education to students with chronic illnesses through such activities as the Summer Institutes conducted by the Oregon Department of Education technical assistance packages, and local workshops. Finally, designate an educational specialist at the Oregon Department of Education to provide expertise to schools who have children with chronic illness.

7. Training

"We need training. Right now, families know more than staff working in the agencies. There is a lack of understanding about chronic illness and very few in-home services."

Karen Pierson
Children's Services Division

Professionals in Local and State Agencies Many families have reported that they are far more knowledgeable about their child's condition, needs, and how the service system is organized and operates than the staff they contact. There is an immediate need to provide training to staff at all relevant state and local agencies about the needs of chronically ill children and their families, services that are available, and ways to access resources. The training can be directed by the Department of Human Resources and may draw from materials and presentations developed at the Oregon Department of Education.

College and University Students

Three state colleges/universities offer certification programs in special education: The University of Oregon, Western Oregon State College, and Portland State University. None of these programs offers a course on techniques for managing students who are chronically ill or medically fragile. Although the likelihood of having students who have serious medical problems is increasing, teachers are leaving their training programs with little information and almost no experience with the implementation of medical protocols. Currently in Oregon there are children and youth in public schools who require clean intermittent catheterization, tube feeding, suction, and ventilation. Clearly, Oregon's teacher training programs are not graduating teachers who are educated regarding such needs.

One way to improve expertise is to define competencies, develop curricula, and infuse this information into special education and regular education teacher training programs. The basic competencies should focus on skills such as understanding medical protocols, demonstrating the understanding of medical procedures, and identifying legal issues which separate medical and educational services.

New Work Roles

In Oregon, as well as nationally, parents are strongly expressing their need for coordinated services, for support for the family, and for safe school environments. Providing appropriate and coordinated support to chronically ill children and their families may require establishing new roles and expanding existing roles of both health and education services in several areas including case management, school health personnel, and home and school aides. For example, having a well-trained aide who could assist a parent with morning care, ride on the bus, and be with the child at school, for many parents may make the difference between being able to keep a child with chronic illnesses at home or placing them in a nursing home; it could also mean the difference between providing and not providing adequate care.

There are many avenues for creating new jobs. One approach that could be easily adopted in the next biennium is for school districts, local human service agencies, and medical service providers to begin examining professional mandates, clarifying and eliminating conflicting administrative rules, and rewriting and developing new job descriptions so that personnel can be hired to fulfill new roles, particularly in the area of family support.

Recommendation: Provide training that will qualify people to work with children who have chronic illnesses and their families.

To help accomplish this, the Department of Human Resources should extend training, particularly about resources and funding models, to staff in state agencies. The Oregon System of Higher Education should take responsibility for building competencies and requiring coursework about the needs of chronically ill children and their families as part of the teacher certification program in Oregon's colleges and universities. School districts, human service agencies, and medical service providers should adopt job descriptions that will enable them to hire personnel to fill new job roles.

V. References

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VI. Appendix

Parent Survey

The Parent Survey used in this report was based on a parent survey prepared by the University of Kansas (Project NEXUX - July 1987) called *A Community Approach To An Integrated Service System*

Oregon Department of Education

July 10, 1988

Dear Parent,

I am working with the Steering Committee on Medically Fragile Children and Northwest Instructional Design, an evaluation company, to develop a report for the Oregon Legislature on the status of services for medically fragile and chronically ill children and their families in Oregon. This report will be completed by the end of this year.

As part of the report format we will be preparing a set of recommendations about needs for improving services. The information about needs will come from recommendations of the steering committee, of representative from various relevant agencies, educators, students and yourselves.

To better discuss the needs of parents I am asking you to complete a survey that has been enclosed with this letter. The survey asks you to identify and list, in order of importance, the major needs that you have as a parent of a chronically ill or medically fragile child.

PARENT SURVEY

Report on Chronically Ill Children and Their Families

1988

Town or City you Live in: _____

Briefly tell us about your child: _____

_____

_____

_____

How old is your child? _____

What is the nature of the services you receive for your child with special needs? _____

_____

_____

_____

_____

_____

_____

Are there services you need that are not available? What are they? _____

_____

_____

_____

We would like to know several things about possible needs that families in Oregon might have. First, we would like to know what services you need to access (but don't have access at the present). Second, we would like to know which services you need financing (but don't have financing now). Finally, we would like you to choose five areas that you feel are most important for the state to support.

Please use the list below and place a check (√) in the 'Need Access' column for those services you need access to, place a check in the Need Financing' column if you need financing for a service. Place a check in the column marked It's Adequate' if the access and financing of the service is adequate. Finally, circle the five services that you feel are most important for the state to support in the next biennium.

If a service you want is not on the this list, please add it.

Need Access	Need Financing	Its Adequate	Service
_____	_____	_____	Respite Care
_____	_____	_____	Parent Support Groups
_____	_____	_____	Transportation to and from Service Facilities
_____	_____	_____	Knowledgeable Occupational/Physical Therapists
_____	_____	_____	A Transition Program (to coordinate the movement of children from one facility/location to another
_____	_____	_____	Access to information about funding sources/services
_____	_____	_____	Knowledgeable Doctors
_____	_____	_____	Knowledgeable Dentists
_____	_____	_____	Parent Education
_____	_____	_____	Appropriate Public Schools
_____	_____	_____	School Nurses
_____	_____	_____	Sibling Support Groups
_____	_____	_____	Counseling/Psychological Services for children with special needs and their families
_____	_____	_____	Medical Care in the Home
_____	_____	_____	Special Equipment
_____	_____	_____	Diagnostic Evaluation
_____	_____	_____	Out-of-Home Placement
_____	_____	_____	Hospital Care
_____	_____	_____	Information to provide public awareness (films, materials, workshops)
_____	_____	_____	Knowledgeable School Staff
_____	_____	_____	
_____	_____	_____	
_____	_____	_____	
_____	_____	_____	

Based on your experiences with your child who has special needs, what, if any, changes would you suggest in the service delivery system? Please describe.

Please identify the category or categories of financial support that help you pay for services for your child.

Private insurance

_____ Offered through work

_____ Privately purchased

_____ Other

Public insurance

_____ Medicare

_____ Medicaid

_____ Other

No Insurance

_____ Tried to get private insurance and did not qualify

_____ Tried to get public insurance and was not eligible

_____ Did not try to get insurance

Medical Care

_____ Child Development and Rehabilitation Center

_____ Easter Seals

_____ Cystic Fibrosis Foundation

_____ Shriner's Hospital

_____ Other

Other Support

_____ Oregon Family Support Services through Mental Health Division

_____ Social Security

_____ Supplemental Security Income

_____ None

Are the total costs that your family pays to provide medical, educational, individual nutritional and other needs of your child:

_____ 10% of less of your income

_____ 11% to 25% of your income

_____ More than 25% of your income

Is there anything we have not covered that you would like to add to this survey? If so, please put your comments here. Thank you very much for your assistance. All information is confidential and your name will not appear in any documents.